

## BOOK REVIEW

### **Crucial Decisions at the Beginning of Life: Parents' Experiences of Treatment Withdrawal from Infants**

H. McHaffie. Radcliffe Medical Press, 2001, £35, pp 440. ISBN 1 8577 5479 4

Hazel McHaffie interviewed 108 parents after their baby died in neonatal intensive care following a decision to withdraw treatment. Over two years, 116 babies died in three neonatal units in Eastern Scotland; 81 families were eligible, and 59 families joined the study (73%). They were invited to opt in to the project by their consultant neonatologists. Some families were not asked, and 11 declined. Interviews usually took place in the families' homes, approximately three and 13 months after their child's death; 90 parents took part in the second sessions.

This fairly high consent rate to such sensitive research is interesting in several ways. It shows that careful ethical procedures can result in reasonable opt in rates. Many mothers and fathers were willing to be interviewed twice on this topic, and they very much want to help to improve services for others. Their varying replies can be taken as covering a wide range of views held by the majority of parents—although the author

honestly notes limitations of her admirable research.

Remarkable improvements in neonatal care now support the healthy survival of many more babies than was possible only a decade or two ago. This book, however, examines who pays the price of progress, and the effects on parents when treatment cannot help their child. They are a significant group. About 75% of deaths in neonatal units follow elective withdrawal of treatment. The book examines where there is scope for improvement in neonatal care for the family, drawing on the anonymous parents' quoted responses. Each chapter ends with recommendations for raising standards of care. The semistructured interviews were tape recorded and intensively analysed, qualitatively and quantitatively. Parents' memories were not validated to check how accurately they accorded with medical records. Yet the research team, including several neonatologists, thought that they generally seemed to be reliable. Memories are real and valid in their own right, in that parents live with these powerful remembrances. "What's important is that you can live with your decision...and that's really difficult," said one mother (page 383). Most parents felt responsible for the decision. They wanted to share explicitly in making the decision, as part of being their child's parent.

The book records several journeys. The researcher travelled around Scotland to meet

the families. A round trip to the islands could last three days, indicating the long distance difficulties that faced some families. The progress of the research project is reported clearly, and voyages through the wide ranging related literature are referred to neatly. The book traces the parents' journeys through pregnancy and birth; neonatal care; making the decision to withdraw treatment; caring for the dying baby; the funeral; follow up hospital care; the effect of the baby's death on the family; support during bereavement, and changes over time of the parents' views.

The research was based at the Institute of Medical Ethics, University of Edinburgh, and was discussed with a group of doctors and ethicists. They reviewed contradictions and complications in data, and the differing knowledge and experiences, power, and perceptions of doctor and parents. This empirical study complements related philosophical texts by encouraging clinicians to rethink policies, concepts of good practice, and the important ethical dilemmas; to be more aware of parents' views, and to review their relationships with parents. This clearly written, absorbing book won the BMA medical book of the year competition, and is highly recommended reading for everyone concerned with neonatal intensive care.

**Priscilla Alderson**  
[p.alderon@ioe.ac.uk](mailto:p.alderon@ioe.ac.uk)